

Web-Based Clinical Trials Information for Patients: An Accrual Aid?

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Background. Slow accrual to clinical trials prolongs trials, increases their expense, and delays medical progress. Accrual is slow for many reasons despite a usually adequate number (in the general population) of patients with the target disease.¹ Even if patients are aware of a trial, their concerns about participation in research^{1,2} frequently preclude their pursuing evaluation for enrollment. Strategies to provide information about trials directly to patients may be effective in improving accrual.³⁻⁵ While the number of on-line patient-oriented trial information resources has increased with the growth of the World-Wide Web, no such resource that we could find fully addressed patients' principal concerns, and most content was written in more sophisticated language than a typical patient could be expected to understand. Furthermore, content quality aside, these resources are useless to the many patients who do not have web access. We developed a comprehensive solution for these problems in the hopes of improving both accrual and patient education about clinical trials.

Methods. We carefully designed a web site to address patients' principal concerns about clinical trials,² giving consideration to a number of known problematic aspects of human-computer interactions.⁶⁻⁷ We developed a tool (intended for use by a clinical trials program's study coordinators) for creating patient-oriented clinical trial information. We used this tool to create a library of such information for the approximately 150 trials currently active in our cancer center's clinical trials program. This system is integrated into our cancer center's existing web server, but its design is not specific to oncology and can be applied easily to other specialties. Periodic evaluations of user interaction with the system helped identify areas for improvement. We are also developing models for kiosk-type touch screen-based workstations to provide access for patients otherwise without it.

Results. Test interactions between patients and the system studied prior to the site's public debut suggest the site will be very helpful to and warmly received in the patient community. The library build will be completed in June 1997, at which time the site will be made publicly accessible. Assessment of accrual impact will be performed after one year of operation. We will present the full results of our pre-debut tests

and the preliminary post-debut results. We will also show the design of the content development tool as well as a sample of the site. Finally, progress on the kiosk models will be reported.

Conclusions. Improved patient education and clinical trial accrual may result from refining the content and method of delivery of the information presented to patients about clinical trials. Improved accessibility to this information for patients ordinarily without access may also provide patients and trials alike with significant benefits. We developed a novel web site and kiosk models to specifically address these concerns. Accrual impact assessment is pending.

Acknowledgements. This work is partially supported by Ortho Biotech, Thermo Information Solutions, and Microsoft Corporation and under a cooperative agreement between the Natl. Institute of Standards and Technology Advanced Technology Program (under the HIIT contract, number 70NANB5H1011) and the Healthcare Open Systems and Trials, Inc. consortium.

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